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A Publication For – and By – IOMSN Members





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COVID-19 Infections in MS & Related Diseases







COVIMS REGISTRY NEWS

he COVID-19 Infections in MS & Related Diseases (COViMS) Registry (www.covims.org) is a collaborative North American effort of the National MS Society (NMSS), the Consortium of MS Centers (CMSC), and the Multiple Sclerosis Society of Canada to obtain deidentified data on SARS-CoV-2 infections and outcomes in patients with multiple sclerosis (MS) and other central nervous system (CNS) demyelinating diseases (eg, neuromyelitis optica spectrum disorder [NMOSD] and MOG antibody disease). The goal of the Registry is to determine if people with these conditions face special risks associated with COVID-19, and if certain disease-modifying therapies (DMTs) incur special risks.

IOMSNews asked Anne Cross, MD, Professor of Neurology at Washington University School of Medicine in St. Louis, MO, where the Registry is based, for an update on the data compiled thus far.

"Data on over 2,000 North American cases of SARS-CoV-2 infection have been placed into the Registry thus far," she says. "We've learned that 62 people among those reported have died—59 had MS and five had NMOSD. Being non-ambulatory or requiring aid to walk increased the risk of a bad outcome from COVID-19. Having comorbidities that have been shown to be associated with worse outcomes of COVID-19 in the general population, such as obesity, chronic cardiovascular disease, and diabetes, were also associated with worse outcomes in people with MS and related demyelinating diseases."

The Registry is only as strong as its data, so all MS clinicians are encouraged to report cases. "Clinicians are asked to voluntarily report cases at least 7 days after the onset of COVID-19 symptoms or a positive test for SARS-CoV-2, and after the course of the infection has become clear," says Dr. Cross, who adds that reporting a case only takes about 10 minutes.



CMSC Annual Meeting Moved to Fall 2021

We are happy to report that the 2021 Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) has moved location and dates to Orlando, FL! Mark your calendars for Monday, October 25-Thursday, October 28, 2021 to attend our hybrid meeting at the beautiful Rosen Shingle Creek. More information about how you can attend both virtually and live will be announced soon, with details about registration, hotel reservations, and much more.

Please visit our website MSCARE.ORG/2021 for all the updates. See you in Orlando!

Letter from the Editor

COVID-19 VACCINES ARE HERE!

elcome to the first issue of *IOMSNews* for 2021. We are grateful to Genentech for continuing their support this year, as we move through the COVID-19 pandemic and beyond.

The big topic right now in medicine is, of course, COVID-19 vaccination, and our lead article in this issue discusses the vaccines in relation to multiple sclerosis (MS) and how to talk to your patients about vaccination. As I write this letter in mid-February,



Marie Moore, MSN, FNP-C, MSCN Editor, IOMSNews

two mRNA vaccines have been approved and a one-dose Johnson & Johnson vector vaccine is being reviewed by the Food and Drug Administration. Unfortunately, just as fast as infectious disease specialists and scientists have come up with these vaccines, new COVID-19 variants have emerged. According to Anthony Fauci, MD, Director of the National Institute of Allergy and Infectious Diseases and one of the most reputable experts in our country on COVID-19, our best hope of controlling this pandemic is to get 70%-85% of Americans vaccinated so we can begin to return to a sense of normalcy. In keeping with this advice, the International Organization of MS Nurses (IOMSN) strongly encourages you as a healthcare professional to get vaccinated as soon as you are eligible in your state, to protect both yourself and your patients.

The Consortium of Multiple Sclerosis Centers (CMSC) and the IOMSN continue to present webinars, links, and other resources on our websites (www.mscare.org and www.iomsn.org) to keep MS clinicians abreast of new developments in the fight against COVID-19—plus information about new drug approvals and advances in MS science. Please take advantage of this information! In addition, in this issue of *IOMSNews*, topics include:

- How to cope with MS nurse fatigue;
- · Assessing MS patients' nutritional health;
- ·A Q&A on MOG antibody disease; and
- · An introduction to the new Midwest Regional Liaison.

Stay safe and stay strong,

Marie

MYTHS AND TRUTHS ABOUT COVID-19 VACCINES AND MS

he first full year of experience with the COVID-19 infection has been one of trial and error, leaving a residue of misconceptions that still exist in practice. Now that two extremely effective vaccines from Pfizer/BioNTech and Moderna are rolling out for widespread administration across the United States and another is being reviewed by the Food and Drug Administration (FDA), it is important that MS nurses and other providers focus on encouraging their patients to be vaccinated as appropriate. They also need to be distributing information that is consistent with the best sources available today.



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sider getting a vaccine as soon as they are eligible to do so rather than trying to optimally time its administration with DMT use, as was previously suggested," says Joan Ohayon, RN, MSN, CRNP, MSCN, an MS nurse with the National Institute of Neurological Disease and Stroke at the National Institutes of Health in Bethesda, MD.

Why mRNA Vaccines Are Different from Traditional Vaccines

Traditional vaccines work by introducing a trace amount of either an attenuated live virus, dead virus, or viral proteins into the body. The goal of vaccine

administration is to trigger a robust immune response at the time of exposure to a particular viral pathogen to prevent an infection from taking place. The Pfizer and Moderna vaccines differ from earlier generations of vaccines in that they are the first vaccines to utilize mRNA to deliver instructions to muscle cells on how to build a protein that in turn will trigger an immune response to a specific viral pathogen (in this case, the SARS-CoV-2 virus). This mechanism promises to deliver higher efficacy and a lower adverse effect (AE) profile to vaccines moving forward. Important facts about the mRNA COVID-19 vaccines include:

- mRNA never enters the cell nucleus where DNA is located, and therefore, will not alter or interact with DNA itself:
- once used to deliver instructions, mRNA breaks down and is disposed of by the body; and,
- the vaccine is unlikely to cause a person to become sick with COVID-19 virus, although it is possible to test positive for the antibodies to the virus after inoculation. This, however, merely indicates the vaccine is working.

Safety of COVID-19 Vaccines for People with MS

Guidelines released in January 2021 by the National MS Society (NMSS) for the use of the two messenger RNA (mRNA) vaccines currently available in the US state that although specific data on patients with MS who may have participated in the vaccine trials are not available, evidence from the general population indicates that the COVID-19 vaccines are safe and effective. As such, people with MS are generally encouraged to get vaccinated when they are eligible to do so. The NMSS guidelines counsel that the mRNA vaccines:

- do not contain live virus and are considered safe for people with MS;
- are not likely to trigger a relapse or worsen chronic symptoms of MS; and,
- are safe to use when taking disease-modifying therapies (DMTs). People taking DMTs are advised to continue with their therapy.

"In an addendum released on February 4, 2021, the guidelines also state that because of the serious health consequences associated with COVID-19 disease, people on DMTs should con-

Adverse Reactions

Reported AEs to the Pfizer vaccine have included common events such as pain, redness, and swelling at the injection site, as well as headache, fatigue, muscle pain, chills, joint pain, nausea, malaise, and lymphadenopathy. While these symptoms may mimic some signs of COVID-19 infection, they are not related to the virus. Most will pass quickly. Avindra Nath, MD, Senior Investigator of the Section of Infections of the Nervous System and Clinical Director of the National Institute of Neurological Disease and Stroke at the National Institutes of Health in Bethesda, MD, observes that, "We've seen very few reactions after millions of injections here and in Europe." He reports that some reactions, such as Bell's palsy, tingling in the face, and mild swelling of the tongue, have occurred. "We are telling people to sit for 15 to 30 minutes in the healthcare facility after receiving the injection to make sure there is no reaction, or if there is one, so it can be treated with oral diphenhydramine and perhaps steroids if necessary," he adds.

Allergic reactions to the vaccine represent the greatest concern. Dr. Nath, who contributed to the creation of the NMSS vaccine guidelines, points out that there is an adjuvant polyethylene glycol component to both the Moderna and Pfizer vaccines that is critical to inducing the immune reaction against COVID-19, but which also can produce side effects in some people, particularly

Essential MS & COVID-19 Vaccine Resources

COVID-19 Vaccine Guidance for People Living with MS

National Multiple Sclerosis Society, January 2021

https://www.nationalmssociety.org/coronavirus-covid-19-information/multiple-sclerosis-and-coronavirus/covid-19-vaccine-quidance

U.S. COVID-19 Vaccine Product Information

CDC, January 14, 2021

https://www.cdc.gov/vaccines/covid-19/info-by-product/index.html



after the second dose. "If the mRNA protein is given just by itself, an immune response won't be adequate," he says. "You must have the adjuvant polyethylene in the vaccine to provoke the creation of antibodies." The side effects are mostly non-severe allergic reactions such as hives, swelling, and wheezing that are typically reported within the first 4 hours of receiving the injection. Some individuals may experience a flu-like illness over the next day or two following the vaccination.

Some accounts by local news media reported on three cases of facial swelling in patients who received the Moderna vaccine that might be associated with recent application of dermal fillers. Botulinum toxin injections were not cited and dermatologists have reported that the condition is not serious, will likely resolve on its own or can be treated with antihistamines and prednisone, and does not change their protocols with dermal fillers.

Anaphylaxis. As of February 10, 2021, the CDC reported that 32 million first vaccine doses had been administered and 8 million people had been fully vaccinated. Another report issued in early 2021 about the Pfizer vaccine by the CDC revealed 4,393 adverse reactions to the initial doses (0.02%), 175 of which were severe. From

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COVID-19 Vaccines (Continued from page 5)

those, 21 cases of anaphylaxis were identified (representing a rate of 11.1 per million doses), 71% of which occurred within the first 15 minutes following injection. It is important to note that 17 of the 21 cases had a history of allergic reactions, and seven had a history specific to anaphylaxis.

"If patients have had a previous anaphylactic response to a vaccine, they shouldn't get the COVID vaccine," Dr. Nath says. For those who have had less severe first responses than anaphylaxis, he offers simple advice for making the decision: "If you have mild allergies, get it. If you carry an EpiPen, don't get it."

Differences in Risks

Presently, there are no clear differences in the risk profiles for the Pfizer vaccine compared to the Moderna vaccine. However, the Pfizer vaccine was tested in 8.5 times more patients than the Moderna vaccine.

Why Widespread Vaccination Is Critical

Vaccination is widely considered the best approach to achieving herd immunity to COVID-19. Originally pointing to a vaccination rate goal of 60% to 70% needed to achieve herd immunity with previous vaccines, Dr. Anthony Fauci and other experts have since suggested that the rate needed for containment of the highly contagious SARS-CoV-2 virus and new variants is around 70%-85%.

Simply recommending to patients that they be vaccinated is not enough. According to a January 5, 2021 article published in *Time* magazine, Gallup and Pew Research Polls report that 37%-40%

COVID-19 Vaccines

No vaccine has yet undergone the FDA's full approval process. According to the CDC, however, as of February 2021, two vaccines have been granted Emergency Use Authorization (EUA) in the US to prevent COVID-19 for the duration of the pandemic, or until authorization is terminated or revoked. These two vaccines are being produced by Pfizer and Moderna:

- The Pfizer COVID-19 vaccine is an intramuscular (IM) vaccine recommended to be given in two doses scheduled 21 days apart.
- The Moderna vaccine is also given IM on a two-dose schedule, 28 days apart.
- The Pfizer vaccine must be diluted, while the Moderna vaccine is given full strength.
- The vaccines are not interchangeable; anyone given one vaccine should complete the dosing with the *same* vaccine.

Mechanisms of Action of mRNA Vaccines

The Pfizer and Moderna vaccines work differently from traditional vaccines that use live or attenuated virus to provoke an immune response, by utilizing state-of-the-art messenger RNA (mRNA) technology. These mRNA-based vaccines do not contain any portion of live virus. And while they

use mRNA, that alone is not enough to produce a specific immune response—the message in the RNA is what is important.

The mRNA in these two vaccines contains a synthetic version of the COVID-19 genetic code delivered in a nanoparticle to the immune cell, along with specific instructions to build a harmless 'spike' protein that emulates the ones on the surface of the COVID-19 virus. The body's immune cells learn to generate antibodies to the practice version of the spike protein that will prevent future infection by the real virus. Once the instructions are delivered, the cell breaks down mRNA and disposes of it, but the cells retain the knowledge of how to respond to the real COVID-19 virus spike.

The most prominent difference between the Pfizer and Moderna vaccines currently available in the US is in storage requirements:

- The Pfizer vaccine needs to be stored at approximately -75°C, which in turn requires a special "cold chain" protocol for transport and handling. Once removed from storage, it can be refrigerated for up to 5 days before it must be administered or destroyed.
- The Moderna vaccine has less stringent handling requirements. It can be kept in a stan-

of Americans have expressed some vaccine hesitancy, which represents a significant roadblock to effectively halting the further spread of the virus. Interestingly, many healthcare workers in nursing homes have expressed hesitancy. Dr. Nath points out that there are no state or federal laws requiring vaccination anywhere in the US. What is needed to reduce hesitancy is additional counseling, he says, with information on the risks versus the benefits of vaccination, particularly in terms of mortality. "Dying from the infection is certainly worse than the potential for vaccine side effects that can be managed," he reports.

A total of 473,223 Americans were reported to have died from COVID-19 as of February 11, 2021, which was ranked the third leading cause of death in 2020, following heart disease and cancer. This is in contrast to reports of six deaths

out of 44,000 volunteers during the Pfizer vaccine trials, four of which occurred in individuals who received placebo and not the vaccine. The two deaths in people who were given the vaccine aligned with normal death rates in the general population during that time. The Moderna trial was associated with 13 deaths, seven of which occurred in volunteers who received placebo rather than active vaccine. It is not yet clear whether the vaccine may be implicated in the other six recorded deaths. Dr. Nath notes that in the first few weeks of distribution of the vaccine, there have been no confirmed deaths from among more than 3 million people inoculated.

Genuine Antivax Concerns

Some concerns about the vaccines are real and not entirely without reason. The *Time* article reported skepticism over the rushed

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dard freezer at temperatures of -20°C, and can be refrigerated for up to 30 days before it expires.

Upcoming Vaccines

Johnson & Johnson/Janssen has a one-shot IM COVID-19 vaccine that is expected to be approved shortly in the US and does not need to be stored at super-cold temperatures but rather merely refrigerated. Rather than an mRNA-based vaccine like the Pfizer and Moderna inoculations, it is a recombinant, replication-incompetent adenovirus serotype 26 (Ad26) vector that encodes a full-length and stabilized SARS-CoV-2 spike protein. The Ad26 vector has previously been used in an Ebola vaccine that was approved in Europe and in investigational vaccines for respiratory syncytial virus, HIV, and Zika virus.

Phase 1-2a clinical data published in *The New England Journal of Medicine (https://www.nejm.org/doi/full/10.1056/NEJMoa2034201)* indicate the IM vaccine is safe in patients from ages 18 up, including older adults. The most common systemic reaction to the vaccine is a high fever, which lasts about 12 hours; other reactions include fatigue, headache, myalgia, and injection-site pain.

Efficacy results show that the vaccine is 66% percent effective at preventing moderate to severe disease and 85% effective at preventing severe disease. There were variations in efficacy against moderate to severe COVID-19 infections, with 72% efficacy in the United States, 66% in Latin America, and 57% in South Africa. The vaccine is protective against the South African variant that is now a major worry to the rest of the world, including the US. The Pfizer and Moderna vaccines have not yet been tested against these variants. In addition, Johnson & Johnson is researching whether a second dose of the vaccine might boost protection.

AstraZeneca has also developed a vaccine in collaboration with Oxford University. It is a non-replicating viral vectored vaccine utilizing a weakened type of chimp adenovirus to model an attack that forms antibodies to COVID-19. This vaccine has run into some roadblocks, particularly in association with protection against COVID-19 variants, and is being reformulated.

Additional candidate vaccines are being investigated around the world for the prevention of COVID-19 infection.

WINTER 2021

MANAGING MS NURSE FATIGUE

How to Care for Yourself

wear-plus into the COVID-19 pandemic, multiple sclerosis (MS) nurses are feeling burned out and fatigued by the demands of the new normal. "At first, we were all adjusting to the new protocols. We were anxious and trying to figure out how to protect ourselves and deliver care safely to our patients who are immunocompromised," reports Tamara Fried, BSN, IGCN, MSCN, a Clinical Infusion and MS Research Nurse at the Michigan Institute for Neurological Disorders in Farmington Hills, MI. "Now, a year later, we are receiving more and more calls about patients who are testing positive for COVID-19 or have been exposed to someone who has COVID. Staff are being exposed, too.

"Many of us aren't eating or sleeping well. We feel anxious. We're not exercising. But we have to keep going for our patients," she notes. Those who are not on the front lines of COVID care may still feel stressed out, and alternately thankful and guilty about not doing more.

Tips for Self-Care

Clearly, the past year has led to compassion fatigue and an accumulation of mental, physical, and emotional exhaustion. Ms. Fried, who

Be on the lookout for these signs and symptoms of stress in yourself:

- Feeling irritation, anger, or denial
- Feeling uncertain, nervous, or anxious
- Feeling helpless or powerless
- Lacking motivation
- Feeling tired, overwhelmed, or burned out
- Feeling sad or depressed
- Having trouble sleeping
- Having trouble concentrating

Source: https://www.cdc.gov/coronavirus/2019-ncov/hcp/mental-health-healthcare.html

attended a Foundation for the Consortium of MS Centers (FCMSC) Mental Health Mini-Mentorship in 2019, offers the following tips for taking care of yourself as well as you care for your patients.

1. Realize you are not alone. "If you are feeling depressed, lonely, and anxious, know that other nurses are experiencing the same feelings," she says. "Talk to your significant other, friends, and family about your day, your mental state, and your frustrations so



Tamara Fried, BSN, IGCN, MSCN Clinical Infusion and MS Research Nurse

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MI

you feel more connected and less isolated."

- 2. Speak up so you can get help. Most Americans are having trouble coping with the pandemic, so there's no shame to admitting you're affected, too. Start by asking about mental health resources where you work. "Most places offer employee assistance programs through the human resources department. You may be able to get free counseling or referrals," she suggests. Alternatively, contact your health insurance company and ask how you can get the help you need. Check out online telemedicine mental health services and smartphone apps, too.
- 3. Get educated about stress and anxiety so you can recognize the signs and symptoms in yourself and others (see box). The Centers for Disease Control and Prevention (CDC) have published information on how to manage stress during the pandemic. Visit: https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/stress-coping/.
- 4. Reach out to the National Suicide Prevention Lifeline at 1-800-273-TALK for help if you feel like you can't go on anymore.
- **5. Get active** to relieve stress and anxiety, sleep better, and take your mind off the relentless news about COVID illness and death. Try yoga, Pilates, or meditation classes, for instance, that rely on deep breathing and help to quiet both the body and mind.

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MOG ANTIBODY DISEASE

A Q&A with Brenda Banwell, MD

You may have been hearing about MOG antibody disease lately in the same breath as multiple sclerosis (MS) and neuromyelitis optica syndrome disorder (NMOSD). For one thing, the COVID-19 Infections in MS & Related Diseases (COViMS) Registry is gathering information on outcomes in people with MOG antibody disease, which has raised its profile. For another, there is now a test for the disease.

IOMSNews interviewed Brenda Banwell, MD, for information about this rare disorder. Dr. Banwell has been studying children with acute demyelinating disease, including MOG-associated disorders, since 1999 and is on an international panel of MOG antibody experts.

Q: What is MOG antibody disease?

A: The international committee I'm affiliated with is working hard to create a formal definition of MOG—which stands for myelin oligodendrocyte glycoprotein—disease. Currently, we describe it as acute demyelination of the central nervous system associated with the presence of MOG antibodies on a blood test. It is not MS, and, in fact, the presence of MOG antibodies argues against a diagnosis of MS. It is also not aquaporin-4 related NMOSD, and it is not as serious a disease as NMOSD. These are three very distinctly and importantly different diseases.

MOG disease is one that affects both children and adults, although it is most often seen in patients' 20s and 30s. Acute demyelination occurs far less frequently in children than adults, but among children under the age of 11 who have a first attack of demyelination of the brain, optic nerve, or spine, 50% of them will have MOG antibodies, while among children ages 11 to 20, 20% will have MOG antibodies.

Q: What are the signs and symptoms?

A: There are many overlapping presentations among MOG disease, MS, and NMOSD. All three groups of patients can present with optic neuritis and inflammation of the spinal cord. In MS, most of the spinal cord lesions are small and focal in nature, whereas those in MOG disease tend to appear as longer, bigger lesions. For patients with MOG-associated disease, recovery from attacks tends to be rapid with minimal disability. In children, over 60% of those with MOG antibodies will only have a single attack, while 30%-40% experience relapses. NMOSD is also characterized by long spinal cord lesions, but the recovery from attacks tends to be variable with a high risk of permanent disability. Most patients with NMOSD experience relapsing disease, and MS is a relapsing-remitting disease in children.

Q: Why are we suddenly hearing about MOG antibody disease now?

A: One of the main reasons is that there is much better testing for MOG disease. The challenge with many disorders is that until you have a very good test, you get a lot of false negatives and positives. An accurate test



Children's

was developed at the Mayo Clinic and at other centers in Europe, and has now been more readily available for about 3 years or so.

Q: How long have researchers and clinicians been aware of MOG disease?

A: We've known that there are patients who have patterns of demyelination, some of whom relapse, that don't look like typical MS. Until the antibody test was developed, we didn't have another name for this disorder. I used to call these cases relapsing non-MS because I felt their course was absolutely atypical.

Q: Has there been an increase in the incidence of the disease?

A: That's a great question, but we don't have the data to answer it. We have increasingly prevalent



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MOG Antibody Disease (Continued from page 9)

recognition of MOG antibody disease. There are no formal prevalence studies because they are extraordinarily expensive to perform—trying to find all MOG patients in a country requires uniform health data, which is rarely available. Prevalence studies in the United States are particularly challenging due to our disparate and separate healthcare-providing systems, which make it difficult to collect data.

The data that we do have, which are quite robust, are that if you present with a first attack of demyelination as a child, the current recommendation is that you should get a MOG test because there is a reasonable probability you might have MOG disease. If you are an adult and your clinical story, magnetic resonance imaging (MRI) results, and spinal fluid tests all point to MS, you don't really need to be tested for MOG disease because it is unlikely to be the cause of demyelination. If you have an atypical presentation of MS, however, the international criteria that are being developed will advise MOG testing.

Q: Is MOG antibody disease genetic?

A: So far, no genetic links have been found for MOG disease. Unlike in MS, there is no linkage to HLA DRB 1501, the strongest allele associated with MS. To the best of our current knowledge, MOG disease doesn't run in families.

Q: Do we know the etiology of the disease if it's not genetic, at least in part?

A: No, we don't really know the etiology for any autoimmune disease. We know that there are some commonalities among autoimmune conditions—for instance, low vitamin-D levels have been associated with MS and MOG disease, but up to 80% of adolescents in North America are vitamin-D deficient due to sun and nutritional deficiencies. However, having low vitamin-D levels does not directly cause autoimmune disease, and most people with low levels do not develop autoimmune diseases.

In children, MOG disease often seems to follow a viral illness, but no one virus has been found to be the culprit and all children under the age

For further reading...

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of 11 have two to five viral infections a year—but again, not all develop MOG or MS.

Q: How is MOG antibody disease treated?

A: If attacks are mild, the symptoms may resolve on their own without medical treatment, although patients always need comprehensive care, counseling, and support. Some patients with moderate to severe attacks may need to be treated with intravenous methylprednisolone for 3 to 5 days. If the attack is severe, they may need plasmapheresis and/or immune globulin. Some clinicians may place them on a monoclonal antibody like rituximab to prevent relapses.

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Where to Refer Patients with Questions About MOG Antibody Disease

The MOG Project – A non-profit patient advocacy organization https://mogproject.org/

ASSESSING MS PATIENTS' NUTRITIONAL HEALTH

s an MS nurse, you're aware that a healthy diet is of paramount importance to your patients' overall health and well-being. You also probably get questions about how your patients should eat, but you don't have the time or expertise to delve into the topic deeply with most of them. "MS nurses, like other nurses and doctors, are typically not trained to counsel patients about nutrition and weight loss," says Mona Bostick, RDN, LDN, MSCS, a dietitian in private practice in Greensboro, NC, who specializes in MS, "or about how people should eat if they have comorbid conditions like obesity, hypertension, or diabetes."

To help prepare you for the questions you'll receive, IOMSNews asked Ms. Bostick for some fast and efficient tips for assessing patients' nutritional status, and for counseling and referring them for further evaluation and management.

Questions to Ask

Ms. Bostick suggests asking patients the following questions based on the DETERMINE checklist developed by The Nutrition Screening Initiative to assess if an individual has nutritional issues:

- 1. Do you have a condition that changes the kind or amount of food you can eat?
- 2. Do you eat fewer than two meals a day?
- 3. Do you eat few fruits, vegetables, or milk products?
- 4. Do you have three or more drinks of beer, hard liquor, or wine most days of the week?
- 5. Do you have tooth or mouth problems that make it difficult to chew and swallow?
- 6. Do you take three or more different prescription or nonprescription drugs a day?
- 7. Without trying to, have you gained or lost 10 lbs. or more over the past 6 months?
- 8. Do you eat alone most of the time?

- 9. Do you have enough money to buy the food you need?
- 10. Are you physically able to shop, cook, and feed yourself?

The answers to these questions as well as any follow-up questions will provide greater insight into the patient's nutrition status and broaden the nutrition conversation beyond "what is the best diet?" and weight loss.

MS nurses, like other nurses

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Mona Bostick,

RDN, LDN, MSCS

hypertension, or

diabetes."



Mona Bostick, RDN, LDN, MSCS Dietitian Food Matters 365, LLC Greensboro, NC

"You want to ask patients to tell you more about their eating issues, and if you can't address

> their questions, you want to refer them to a dietitian," she says, adding that most people who receive an MS diagnosis may benefit from a nutritional consultation. Many health insurance plans also cover several follow-up visits with a dietitian each year for people with MS, she reports, and plans are more likely to cover these visits if a patient is referred to the dietitian by a clinician.

> "What you don't want people to do is to turn to 'Doctor Google' for advice," she says. "There is so much information available on the Internet that is not credible or helpful and may even be dangerous." For one thing, there is no such thing

a variety of dietary strategies published on the Internet that purport to benefit people with MS. Eating well is *not* defined differently because of an MS diagnosis, but patients may fall prey to false claims about these diets as well as about supplements.

"There are many diets, regimens, and protocols promoted by functional medicine and other alternative or unconventional health practitioners" Ms. Bostick says. Examples include The Wahl's Protocol, the Autoimmune Protocol

as an anti-inflammatory "MS diet," yet there are

(Continued on page 18)

Assessing Nutritional Health (Continued from page 17)

(AIP), the Best Bet Diet, and the Swank Diet. The Swank Diet, which is essentially a hearthealthy diet, is not harmful but will not impact the MS disease course. However, many other regimens are very restrictive, encouraging avoidance of entire food groups, and they lack evidence to support the claims they make. On the other hand, the Mediterranean and DASH diets are broadly health-promoting and may be beneficial to patients with MS. Intermittent fasting, where people fast for 12 hours a day or eat only 500 calories three days a week, is also being studied in the MS population, but should not be recommended to patients because it is contraindicated for anyone with diabetes or a history of disordered eating, of which you may not be aware.

Talking About Weight Loss

When it comes to weight loss, Ms. Bostick suggests focusing on nutrition-related health benchmarks and the nutrition recommendations that impact them before focusing on weight. For example, if a patient is carrying extra weight and has comorbid health conditions such as type 2 diabetes, hypertension, or elevated blood fats, focus on the nutrition interventions that will bring benchmarks into the healthy range. Weight

loss may follow, but improving these benchmarks will result in improved health regardless of weight loss.

Ms. Bostick notes that simple messaging is best and recommends focusing on what to add rather than what to restrict: "Suggest that patients eat more vegetables. Eat more whole grains. Eat a greater variety of colorful plant foods. Make the message as small and specific as possible to that individual." If more detailed nutrition guidance is warranted or desired, a referral to a dietitian is recommended.

Assess and Refer

By doing a quick nutritional assessment of your patients on at least a yearly basis, you can do a lot to help them eat better and manage their health. What's more, compiling a list of dietitians in your area that you can refer your patients to can take the burden of being a nutritional expert off your plate. "You want to catch nutritional issues that might otherwise go under the radar, but you don't have to manage them yourself," says Ms. Bostick. "At the moment, dietitians aren't typically included as active members of interdisciplinary MS teams, but we are hoping to play a larger role as we learn more about eating well with MS."

How to Assess Your Own Diet

Nurses, like their patients, may need help to eat better, especially during stressful times. Here are Ms. Bostick's suggestions.

Avoid skipping meals. Not eating will lead to dips in your blood sugar that will leave you vulnerable to overeating when you do eat. "It's best to set a routine for eating—whether it's three square meals a day or five smaller meals—and stick to it to keep your blood sugar on an even keel and lower your stress level," she says. You might even set a timer on your phone to remind yourself to eat regularly (at least every 5 hours).

Plan ahead what you'll eat. Often, we reach for what is most convenient, which may not be the healthiest option. It's a good idea to make a list of healthy snacks and meals to buy and keep your kitchen stocked up with those items. *Recommended snacks*: apple slices or graham crackers

with nut butter, snack bars like Kind or Lärabars, plain Greek yogurt with granola, fruit, and/or a teaspoon of jelly or jam mixed in, mozzarella or other cheese sticks, or a handful of nuts.

Include carbs, protein, and fat at every meal. Carbohydrates give you immediate energy while protein promotes satiety and supports immune function, among other benefits. Healthy fats help the body to absorb fat-soluble vitamins.

Avoid highly refined foods, which tend to contain large amounts of sodium, added sugar, and other potentially unhealthy ingredients like trans fats.

Eat intuitively. Many people tend to snack out of boredom or stress, especially at night. Before you open the refrigerator, check in with yourself to see if you're really hungry or if you're trying to self-soothe feelings like anxiety or restlessness. In those cases, it would be better to take a walk, call a friend, or take a nap than eat.

MEET YOUR NEW MIDWEST LIAISON AMY GILBERT, RN, MSCN

he International Organization of Multiple Sclerosis Nurses (IOMSN) would like to welcome Amy Gilbert, RN, MSCN, as the newest Regional Liaison serving the Midwest. "I volunteered for this position because I want to get more people involved in MS nursing," she says. "I love educating new nurses who are excited about MS, and I learn from them myself. I also think the IOMSN is a great way for MS nurses to network and trade information with each other via the IOMSN forum and virtual and eventually again in-person

meetings." Right now, she is particularly gratified to be able to connect with fellow IOMSN members to discuss trends and new information, and communicate with other nurses about how they are practicing. "I can ask questions and have other nurses answer the questions from their practice perspective," she says.

Like other IOMSN Regional Liaisons, Ms. Gilbert has a special understanding of the healthcare needs and services in her area-which includes Minnesota, Iowa, the Dakotas, Wisconsin, Nebraska, Kansas, Missouri, Illinois, Michigan, Indiana, and Ohio-that makes her a valuable resource to MS nurses. She plans to conduct outreach efforts in 2021 first in the Minneapolis region, starting with the Schapiro Center for MS where she works, as well as the Noran Neurological Clinic and the Minneapolis VA Health Care System. Through her contacts at local hospitals, Ms. Gilbert would like to find ways to give talks on neurology floors. "I can answer questions about the IOMSN and MS, and bring information to people who deal with MS every day but don't specialize in it the way I do. I want to make sure nurses and patients in my area get evidencebased information, because there is so much misinformation out there, and MS treatments are so complicated," she says.

Ms. Gilbert notes that in the past, both the Schapiro Center and the Minneapolis National MS Society have sponsored brown-bag lunch meetings for nurses, which offer the perfect



Amy Gilbert, RN, MSCN Clinical Nurse Schapiro Center for Multiple Sclerosis Minneapolis, MN

opportunity "to mention the IOMSN and how much I've gotten out of membership." When she talks to new nurses about MS infusion therapy, she also explains the value of becoming an MS certified nurse (MSCN) to them.

An MS Career Begins

Ms. Gilbert came to MS nursing from a background in critical care and infusion nursing. She received her RN in 2003 and started working at the Schapiro MS Center as an infusion nurse in 2012. "I knew nothing about MS until I came

to the Schapiro Center," Ms. Gilbert says. The patients taught her about their experiences with MS while receiving their infusions and made her want to learn more about the disease. "You really build relationships with patients when you work in an infusion center and see them frequently. I wanted to know what I was talking about when they asked me questions and to be an integral part of this MS healthcare group," she adds.

Ms. Gilbert joined the IOMSN after attending the Consortium of Multiple Sclerosis Centers (CMSC)/IOMSN Annual Meeting in 2014. "I went to the IOMSN nurse dinner and I was wowed by all of the nurses I saw and met there, and I wanted to be like them. I was amazed by the knowledge and passion of these nurses," she says.

At that first CMSC meeting in 2014, Ms. Gilbert followed the *Fundamentals in MS* track, a multi-day course given at recent CMSC Annual Meetings with sections on different topics by leading experts in the field. "That gave me a really good foundation in MS and helped me study for the MSCN exam, which I passed in 2015. The course covers so much about MS, including the history, epidemiology, immunology, natural history, and diagnosis," she states, adding that there's also a wealth of cutting-edge information on the different types of treatments for relapsing and progressive forms of MS, as well as the psychological impact of the disease and treatment, integrative medicine, and comprehensive

(Continued on page 20)

Meet Amy Gilbert (Continued from page 19)

care approaches working with a multidisciplinary team.

"As I got to know more about MS, how the immune and central nervous systems work, and how the medications work, it kept spurring more questions. I realized I really needed to be a provider, to share my knowledge and help these patients," Ms. Gilbert recalls. "We have a high prevalence of MS in Minnesota," she explains,

"and I saw a great need for specialized care in rural areas."

Because she was so enthusiastic about patient care, the Schapiro Center's medical director, Jonathan Calkwood, MD, and nurse manager Brenda Brelje, RN, MSCN, suggested she move to clinical care, where Ms. Gilbert has been working directly with MS patients on all aspects of their care since 2015. "As a clinical nurse, I plan, direct, and coordinate daily patient care activities, implement nursing interventions, take detailed histories from all new patients, and collaborate to create office protocols for standards of practice related to medication management and laboratory and infusion procedures," she says.

Challenges in MS Care

Ms. Gilbert points out that there are major challenges for people

with MS and their healthcare providers, particularly as a result of the COVID-19 pandemic and shutdowns. "There were a lot of things we were now," she says, with the need for medical services to be delivered remotely as much as possible, which not all providers were prepared for. "We all became nurses because we care about people and how we care for them has changed dramatically over the last 9 months," she says, adding that her center did not offer telemedicine at the start of the pandemic, and a system had to be developed and implemented almost immediately. "It's hard to say how telemedicine will continue to be used in the future," she observes, "although it would be helpful given the wide regional cover-

age needed in areas of the Midwest where there aren't many MS providers."

As a future goal, Ms. Gilbert says December 2022.

On the personal side, Ms. Gilbert and her husband Lateef are parents to three children: Emilie 22, Caitlyn 19, and Jayden 13. The family resides in Lakeville, MN. When asked what she does in her downtime, Ms. Gilbert laughs and says, "I work full time, take care of my family, and

I go to school, so schoolwork is my hobby right now. When I have free time, though, I love to garden. I love the creative aspect of planning garden arrangements and seeing the flowers and vegetables in summer. I think everyone, and especially healthcare providers, needs an outlet that brings them happiness."

Looking Ahead

she would love to continue to conduct virtual meetings for nurses and their patients with mobility and transportation issues after the pandemic ends. She is also currently working toward a degree as a nurse practitioner through Simmons University in Boston, via an online platform. She hopes to earn her degree by

doing before the pandemic that we can't do right

— AMY GILBERT, RN, MSCN



Encourage Your Patients to Visit LiveWiseMS.org

Information is power, and the right information is empowering. LiveWiseMS.org is a premier MS resource that seeks to empower patients with MS, their care partners, and healthcare professionals by providing trustworthy, evidence-based information about the disease and its treatment.

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IOMSN LIAISONS

OMSN is committed to making the organization as accessible as possible. Regional Liaisons are knowledgeable, experienced nurses who live and work in communities across the country and the world. They are available to assist you in accessing the information that you need.

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1 Professional Development

Each year, the IOMSN provides dozens of webinars, live programs, and print resources that convey the latest evidence-based information on the assessment, diagnosis, and treatment of MS.

2 Collaboration

The IOMSN is dedicated to fostering working relationships between nursing professionals. One of many means of doing this is the IOMSN Forum—commonly referred to as the IOMSN Google Group—an online resource for members to exchange ideas, ask questions, and share their knowledge.

3 Connections

Participating in IOMSN activities is a great way to network, stay up to date on important trends and career opportunities, and forge enduring professional relationships and personal friendships.

4 Support

The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support when possible for members' research endeavors, and provides a host of resources that enhance nursing professionals' ability to advocate for themselves and their patients.

5 Recognition

In conjunction with the Multiple Sclerosis Nurses International Certification Board (MSNICB), the IOMSN has developed an examination for registered nurses that leads to designation as an MS Certified Nurse, or MSCN. Additionally, each year the IOMSN recognizes outstanding individual contributions to MS nursing through its annual awards program.

Visit our website at http://iomsn.org/ or call us at 201-487-1050

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COVID-19 Vaccines (Continued from page 7)

timeline in which the vaccines were created, since all previous vaccines have taken many years to develop. This concern can be countered by explaining that the vaccines currently in use were the product of many years of work already in progress, which allowed for a significant reduction in the usual multi-year exploration of entirely new vaccines.

The exceptional efficacy of 95% reported in clinical trials for the two mRNA vaccines from Pfizer and Moderna has also been challenged for seeming "ridiculously high," *Time* reported. This again, could be attributed to the extremely abbreviated study period and the fact that mRNA vaccines are designed to deliver greater efficacy than traditional vaccines.

Managing Deliberate Misinformation

Other concerns often posed by antivaxers include false claims about vaccine side effects. "Marketers have known for years that negative campaigns are more influential and persuasive than positive campaigns," Dr. Nath reports. For instance, investigation into a possibly bogus post to Facebook by a nurse claiming that she developed Bell's palsy following her first vaccination showed that no such nurse appeared to exist. Still, the damage was done. The reality is that in the clinical trials, four cases of Bell's palsy were reported among the 22,000 Pfizer vaccine recipients or approximately 8 per 10,000, which appears only moderately higher than the normal incidence of Bell's palsy, estimated at approximately 23 per 100,000 people per year.

Dr. Nath and Ms. Ohayon agree that the most effective way to turn around patients who have been misled by antivax claims is to lead by example. "I had a cousin who was anti-vaccination," Dr. Nath says. "I got vaccinated and she asked how I felt about it. I said it was an historical moment in human history and I was glad to be part of it. That convinced her and she said, okay, she'd try it."

Ms. Ohayon adds, "There is a lot of misinformation out there, so make sure you have good sources of information to counter it. Listen to patients, educate them, correct misinformation, and reassure them that for most people the benefits of vaccination are greater than the risks."



INTRODUCING MS TEAMWORKS 4.0!

An inspiring collection of videos from MS patients, clinicians, and caregivers

New videos have recently been added. Topics include:

- Keys to Overcoming Anxiety and Navigating Depression While Living with MS
- What If MS Is Not the Only Chronic Condition?
- How Do I Know If This Is a Relapse?
- What's the Role of Occupational Therapy in MS Care?
- Strategies for Working While Living with MS
- Leaving the Nest with MS
- Reflections from a Mother Living with MS
- Pathways for Dating While Living with MS
- Best Technologies for MS Care
- Developing Trust and a Partnership with Your MS Team
- COVID-19 and MS: What's the New Normal?
- Differences Between Relapsing-Remitting MS and Progressive MS

Visit https://msteamworks.com/to learn more and view the videos.

Thank you to our generous supporters: Biogen, Bristol Myers Squibb, EMD Serono, Genentech, Novartis, and Sanofi Genzyme.

Nurse Fatigue (Continued from page 8)

"I have found free tap and ballet classes online, as well as yoga classes," says Ms. Fried, "I've danced and taught dance my whole life. Taking these classes was a lot of fun!" Google and look on social media for classes, and ask friends if they know of any good virtual classes.

- **6.** Go outside if you can. Fresh air is invigorating and can clear your mind. Take your dog for a walk, or walk or run on your own. If the courts are clear, you can even play socially distanced games like tennis and pickleball outdoors during cold weather.
- 7. Take up hobbies that help you unwind and relax. Try reading, knitting, crocheting, crossword or jigsaw puzzles, home improvement projects, sewing, cooking, or baking.

- 8. Manage your alcohol consumption if you drink. Women are advised to have no more than one alcoholic drink a day. Avoid other substances.
- 9. Take time to decompress after work. Steer clear of the news and the pandemic for a while and take a nap or a bath, or have a cup of tea while you read a good book for half an hour. "In the warmer weather, I like to sit on my balcony in the sun after work," says Ms. Fried.
- 10. Be kind to yourself and keep hope for a better future. The COVID vaccines are now being administered and things will hopefully improve quickly over the next few months. Till then, try to focus on the good things in your life—your family, your patients, your friends, your pets—and think toward the future.

MOG Antibody Disease (Continued from page 10)

However, just because you test positive for MOG antibodies and you have a first attack doesn't mean you will have a relapse. Only 25% to 30% of children with a first event and MOG antibodies have relapsing disease. We bring these patients in every 3 months for clinical visits.

There are no trial data available yet, but personally, I do not put these patients on a chronic therapy unless they have a second attack. Some patients, typically adults with MOG antibody disease, are prescribed 3 to 6 months of oral

prednisone therapy after an attack to prevent a relapse, but I don't recommend that due to the risk of weight gain and other side effects.

There are lots of gaps in our knowledge, and I humbly admit that, but the international community working on MOG disease is energized to solve these important questions like how to treat attacks and appropriate next steps. We need evidence-based treatment guidelines, but the progress we've made so far is encouraging.



COVID-19 Infections in MS & Related Diseases







To obtain additional information about this joint effort or to report a case of COVID-19, please visit:



www.covims.org

COVID-19 Infections in MS & Related Diseases (COViMS) is a joint effort of the Consortium of MS Centers (CMSC), the National MS Society (NMSS), and the Multiple Sclerosis Society of Canada (MSSC) to capture information on outcomes of people with MS and other CNS demyelinating diseases (neuromyelitis optica and MOG antibody disease) who have developed COVID-19. Together, the CMSC, NMSS, & MSSC along with several independent experts launched this very important effort on Thursday, April 3, 2020.

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